



**NJ Department of Health
Governor's Council for Medical Research and Treatment of Autism
Council Meeting Minutes (ratified)
June 3, 2019**

Council Members Present

Michael Aquino, MD, F.A.C.G., Senate President Appointee; Partner, Shore Gastroenterology Associates; COO, A2Z Diagnostics

Cheryl F. Dreyfus, Ph.D., Academic Institution Representative; Professor and Chair, Department of Neuroscience and Cell Biology, Rutgers University, Robert Wood Johnson Medical School, present via teleconference

***Caroline Eggerding, MD**, Healthcare Organization Representative; Division Head, Department of Pediatric Neurology and Development, Cooper Children's Regional Hospital

Susan P. Evans, Ed.D., Commissioner of Health Appointee; Education Program Specialist for Early Intervention Program, NJ Department of Health

Ketan Kansagra, MD, FAAP, Academic Institution Representative; Neonatologist, Division of Neonatal Medicine, Children's Hospital of New Jersey at Newark Beth Israel Medical Center

Thomas V. Macchiaverna, MA, Public Member Representative; Special Education Teacher

Michele Sorvino, RDMS, Speaker of the General Assembly Appointee; Executive Director, Golden Door International Film Festival of Jersey City

*Denotes Council Chairperson

Absent

Wilma Judith Friedman, Ph.D., Academic Institution Representative; Professor, Department of Biological Sciences, Rutgers University

B. Madeleine Goldfarb, MA, Autism Organization Representative; Founder/Director of the Noah's Ark Institute

Samuel Sheng-Hung Wang, Ph.D., Academic Institution Representative; Professor,
Department of Molecular Biology and Princeton Neuroscience Institute, Princeton University

Gary Weitzen, BA, Autism Organization Representative; Executive Director of POAC (Parents of Autistic Children)

NJ Department of Health (NJDOH) Attendees

Linda N. Bocclair, M.Ed., MBA, Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 1
Governor's Council for Medical Research and Treatment of Autism
Commission on Brain Injury Research and Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant
Scientific Planning Consulting

Public Attendees

Liz Torres, Ph.D., Rutgers University
Deborah Spitalnik, Ph.D., Rutgers University, Boggs Center
Susie Budine, Director of Education Services, Highland Park School District
Richa Rai, Rutgers University
Caroline Coffield, Ph.D., Rutgers University, Boggs Center
Rich Dreyfus
Sofia Sorvino

Note: Motions are numbered.

I. Welcome - Council Chairperson Dr. Caroline Eggerding called the meeting to order at 6:10 PM and welcomed everyone.

II. Public Meetings Act Announcement - Dr. Eggerding read the Public Meetings Act.

III. Approval of the March 4, 2019 Meeting Minutes-Dr. Eggerding called for a motion to approve the March 4, 2019 meeting minutes. MOTION by Dr. Dreyfus to approve the minutes was seconded by Dr. Kansagra.

1. MOTION to approve the March 4, 2019 meeting minutes was passed with five members in favor and two abstentions.

IV. Presentation by Deborah Spitalnik, Ph.D., Final Research Report CAUT15APL014

Deborah Spitalnik Ph.D., Principal Investigator, presented her research on *Exploring the experiences of diverse families of children newly diagnosed with ASD in New Jersey*

The goal of the 2-year pilot project was to understand the experiences of Latino families after their child was diagnosed with ASD. Specifically, it investigated the families' experience receiving an ASD diagnosis for their child and explored their linkage with recommended follow up services for their child, including any barriers.

Dr. Spitalnik described the six cross-cutting themes that emerged across the interviews conducted around six months and one-year post receipt of the autism diagnosis. Findings from this project will provide an understanding of relevant facets of Latino family structure, cultural beliefs, and views about child development, disability, and healthcare. These findings will also provide an evidence base to assist clinicians and service systems in providing services to Latino children with ASD and their families that are more culturally sensitive, relevant and competent.

The ways that the data from this project will highlight this changing conceptualization of autism among Latino families is an interesting and important contribution. A manuscript that describes this, as well as the other overarching themes, is in preparation for submission.

The presentation was followed by a Q&A session. Dr. Eggerding, on behalf of the Council, thanked Dr. Spitalnik for her most informative presentation.

V. Continuation Funding for CAUT17APL025, A Pilot/Feasibility Study of the Use of High Dose Propranolol to Treat Severe and Chronic Challenging Behaviors in Adolescents and Adults with Autism Spectrum Disorders. Dr. Eggerding referred to the grantee's progress reports and critiques of the reports by the primary reviewer included in the Council's meeting packets. Dr. Eggerding called for a motion to approve continuation funding for the second year of grant CAUT17APL025. MOTION by Dr. Aquino to approve continuation funding for grant CAUT17APL025 was seconded by Dr. Evans.

Discussion: The primary reviewer recommended approval to continue funding the second year of the grant noting "...the investigators achieved IRB approval and are on track to initiate recruitment aligned with grant priorities". Members considered requesting a review of progress in six months given the primary reviewer's comment that "...an updated timeline of recruitment activities would be helpful to understand when recruitment is now projected to be completed".

2. Motion to approve continuation funding for CAUT17APL025 was passed with six in favor and one recusal.

VI. Continuation Funding for CAUT18ACE014, New Jersey Center for Excellence at

Rutgers. Dr. Eggerding referred to the grantee's progress reports and critiques of the reports by the primary, secondary and reader reviewers included in the Council's meeting packets. Dr. Eggerding called for a motion to approve continuation funding for year two of grant CAUT18ACE014. MOTION by Dr. Aquino to approve continuation funding for grant CAUT18APL014 was seconded by Ms. Sorvino.

Each of the three reviewers (Primary, Secondary and Reader) recommended approval to fund the second year of the grant. Comments included "...moving ahead fine... excellent effort to carry out many complex objectives...overall (self-reported) progress good...doing a truly impressive job". Recommendations/observations included "...recruitment of research participants for translational research should be a high priority for year 2... research participation is the lowest, but they are working on it... need to develop and implement a new venue and core curriculum for a degree-conferring ABA therapist program given the proposed program is not feasible at Rutgers".

No discussion.

3. Motion to approve continuation funding for CAUT18ACE014 was passed with six in favor and one recusal.

VII. NJACE Presentation by Elizabeth (Liz) Torres, Ph.D.

Liz Torres, Ph.D., Principal Investigator, NJ Autism Center of Excellence (NJACE), reviewed the goals of the NJACE and provided the following examples of activities and outcomes accomplished during the first year of the grant:

- Created a dynamically interactive website (<https://njace.us/>) providing researchers, clinicians and the public information about grants and new and ongoing activities.
- Established the NJACE Professional and Community Advisory Board. The Board provides guidance to identify research and training gaps and assist in setting priorities.
- Planning a five-session advanced grant writing workshop with the intent to increase the pool of applicants for Council funded grants.
- Implementing a comprehensive plan to recruit research participants, a need identified by Council grantees.
- Provided ADOS-2 Clinical, Toddler and Advanced training to expand skills of clinicians and pool of research-reliable staff to assist researchers.
- Sponsored three Brain Storming Events (BSEs)-Technology for autism with IBM; Transition and Employment; Young parents & Under represented populations.

- Created the NJACE Faculty Scholarships with the goal to enhance ASD-related skills of pre-service students (awarded 1 and currently receiving applications for 2nd).
- Offering Adult Issues webinar series to clinicians, researchers and other stakeholders to address the need for better training/attention to adults with ASD.
- Conducted multiple workshops (diagnosis and behavior management; ASD, Anxiety and Trauma; addressing the needs of ASD patients in medical settings) for clinicians, researchers and other stakeholders.
- The NJACE Conference for grantees is scheduled for June 4, 2019.
- NJ Consortium of Technology for Autism Conference is scheduled for October 2019.
- Planning 2020 conferences, one NJ dental practices and one for medical providers.

Dr. Eggerding, on behalf of the Council, thanked Dr. Torres for her most informative presentation.

VIII. Review Rules of Order- The following rules were brought to the attention of the Council:

ARTICLE III: COUNCIL MEMBERSHIP AND STRUCTURE, Section 2., Conduct of Council Members

Members who receive requests, including those from grantees, for input or participation, must contact the Director as a matter of procedure and to avoid putting Council members at risk for triggering conflicts of interest/recusal requirements. The Director will consult with the Council Chair, as appropriate.

Note: A member was recently asked to participate in an activity sponsored by a grantee and was concerned about the potential for conflict of interest/triggering recusal. The NJDOH Ethics Officer reviewed the request and informed the member there would be no conflict of interest in participating in the activity.

ARTICLE IV: OFFICERS OF THE COUNCIL, Section 1., Chair

At its first meeting of each calendar year, the Council shall select, by a simple majority of the members present, a chairperson from among its members, who shall serve as the chairperson until the first meeting held in the next calendar year, at which time the same person may be selected as chairperson or a new chairperson may be selected in the same manner.

Note: Council Chair Dr. Caroline Eggerding encouraged each member to consider accepting a nomination to serve as Chair in 2020 when Council votes in March 2020. She described the rewards and challenges of serving as Chair. Although Dr. Eggerding will not consider a nomination to serve in 2020 she will continue serving on the Council as the Health Organization Representative.

ARTICLE II: COUNCIL RESPONSIBILITIES AND DUTIES, Section 1. Responsibilities and Duties, Director

In reviewing the extensive list of duties of the Executive Director, Dr. Eggerding emphasized the important role of the Executive Director in fulfilling the requirements of the statute (P.L. L.2007, c.168, 30:6D-61) in addition to duties recommended by members and reported in the Final Report of the Council's June 2016 Strategic Planning Meeting. Note: Sadly, Dr. Martin T. Zanna passed away on February 5, 2019 after serving as the Acting Executive Director for the Council since 2011. The NJDOH is currently recruiting for an Executive Director.

IX. Defining Clinical Research and FY19 Fellowship Updates- Dr. Daphne Robinson commented the Council has been using the now-outdated NIH definition of clinical research that includes any project involving humans. Research projects that meet this definition but focused on biological specimens are essentially basic research, and fare better in review.

She presented NIH's expanded definition of a [Clinical Trial](#): any "*research study in which [...] human subjects are prospectively assigned to one or more interventions*". This includes studies with behavioral interventions or only healthy participants. This includes studies that use an intervention for the purposes of understanding fundamental aspects of a phenomenon; such trials are now called [Basic Experimental Studies with Humans](#) (BESH).

Starting with the FY20 grant cycle, studies that focus on biological specimens or health information will be funded as part of the basic research program.

FY19 Fellowship Update: At the March 4, 2019 Council meeting, members approved funding for a fellowship grant application (CAUT19AFP003), from Princeton University. It was later discovered the Principal Investigator (PI) received a fellowship grant from the Humboldt University of Berlin. Princeton University requested the NJDOH agree to comply with the cooperative agreement between Princeton University and Humboldt University of Berlin. Legal documents are being reviewed by the NJDOH.

X. Report of Revenue and Expenditures- Copies of the Report of Revenues and Expenditures were sent to the Council members for their information.

XI. Public Comments -Susie Budine, Director of Education Services, Hyland Park, described her experiences working with middle and high school students with autism, including initiatives that have been successful. She spoke in support of Dr. Torres and ideas they discussed for potential areas of research and recruitment of participants through the school system.

XII. Adjournment Dr. Eggerding asked for a motion to adjourn.

4. MOTION to adjourn by Dr. Evans and seconded by Dr. Dreyfus was passed with all members in favor. The meeting was adjourned at 8:45 PM.